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PERCUTANEOUS ENDOSCOPIC GASTROSTOMY IN GERIATRIC PATIENTS WITH DYSPHAGIA

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Percutaneous endoscopic gastrostomy in geriatric patients with dysphagia

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To my mother who struggled.

If I say "the older person" who do you see in front of you,
who are you thinking about?

Susanne Rolfner Suvanto

ABSTRACT

Background: Orofaryngeal dysphagia (OD) is common in geriatric patients and a risk factor for malnutrition and prolonged in-hospital stay. Nutritional assessment is essential in these patients and documentation should be performed. Enteral nutrition (EN) by percutaneous endoscopic gastrostomy (PEG) is a common treatment to ensure nutrition status for patients with OD.

Aim: The overall aim of this thesis was to increase the knowledge of the process of geriatric patients receiving PEG regarding indication, survival, documentation of nutrition assessment and complications.

Aim study I: To examine the indications for and survival in a consecutive group of elderly individuals who had received PEG.

Aim study II: To describe to what extent nutritional assessment were performed and documented in the records of older patients with stroke treated with EN by PEG. A secondary aim was to identify documented post-procedural complications after PEG insertion during hospital stay.

Methods: Both study I and study II were retrospective. Data were collected consecutively from records of patients 65 years and older, who received PEG, admitted to the hospital during a 4-year period.

For Study I collected data included age, gender diagnosis, indication for PEG, operating time, removal time, or time of death. Data were analyzed and presented with descriptive statistics as mean (±SD) and median. For survival analysis the Kaplan Meier curves were used.

For Study II data were collected from three stroke units. Collected data included patient characteristics, nutritional status, multimorbidity, post-procedural complications and pressure ulcers. Data were analyzed and presented with descriptive statistics as mean (± SD) except LOS and number of days from hospital admission to PEG insertion which were presented as median (range). For correlation analyses, Spearman correlation coefficients were calculated. Ethics: Both studies were performed according to the Helsinki declaration guidelines.

Results: In study I records of 201 patients 79 ±7 years were included and in study II patient records of 161 patients 82,2 ±7 years were included. The main findings of this thesis are the following, in study I OD was an indication for PEG in the 86% of geriatric patients. The median survival in this group was about 4 months and the 30-day mortality was 22%. The patients were categorized into seven diagnosis groups. Patients with stroke and other neurological diseases as well as patients with malignancies had the shortest survival rate. Almost 80% of the patients in

study II fulfilled the European Network criteria for multimorbidity. Morbidity and multimorbidity correlated to the length of stay ($p = < 0.0005$). Postprocedural complications occurred in 69% of the patients. More than one complication occurred in 33% of the patients. The number of complications was related to weight loss ($p = < 0.046$) and Body Mass Index (BMI) change ($p = <0.018$). One of the major findings was that pressure ulcers (PU) was identified in 50 % of the patients as documented in the patient records.

Conclusions: OD in patients with neurological disease constituted a majority of the patients who received PEG in study I. Survival after PEG insertion varied for patients in the seven different diagnose groups. Furthermore, in study I the severity of the patient's diseases are unknown. It is also unknown whether the severity of the disease could have had an impact of the mortality of the patients. In study II essential information of the patient's nutritional status was missing which could have had an impact the patient's nutritional treatment during the hospital stay. The identified frequency of pressure ulcers which was an unexpected complication and indicates that there is a need for further research. This study indicates that implementation of nutritional guidelines in the health care of geriatric patients with PEG is needed.

Keywords: elderly; enteral nutrition; gastrostomy; mortality; PEG; survival; percutaneous endoscopic gastrostomy; stroke; oropharyngeal dysphagia; nutritional assessment; post-procedural complications; pressure ulcers

SAMMANFATTNING

Bakgrund: Orofaryngeal dysfagi (OD) är vanligt hos geriatriska patienter och en riskfaktor för undernäring och förlängd vårdtid. Nutritionsbedömning och dokumentation av denna är nödvändig för dessa patienter. Enteral nutrition (EN) via perkutan endoskopisk gastrostomi (PEG) är en erkänd behandling för att säkerställa nutritionsstatus för patienter med OD.

Syfte: Det övergripande syftet med denna avhandling var att öka kunskapen om geriatriska patienter som erhållit PEG angående indikation, överlevnad, dokumenterad nutritionsbedömning och komplikationer efter inläggning av PEG.

Syfte delarbete I: Att undersöka indikationerna för och överlevnaden hos geriatriska patienter som erhållit PEG.

Syfte delarbete II: Att beskriva i vilken utsträckning nutritionsbedömning dokumenterades i journalerna för geriatriska patienter med stroke erhållit PEG. Ett sekundärt syfte var att identifiera dokumenterade komplikationer under vårdtiden efter inläggning av PEG.

Metod: Både studie I och studie II var retrospektiva. Patientjournaler inkluderades konsekutivt och information samlades in för patienter 65 år och äldre, som erhållit PEG, under en fyraårsperiod.

Insamlade data i studie I avsåg kön, ålder, indikation för PEG, tid för inläggning av PEG, tid för borttagning av PEG och dag för dödsfall. Data analyserades och presenterades med beskrivande statistik som medelvärde (± SD) och median (range). För överlevnadsanalys användes Kaplan Meier-kurva.

För studie II inkluderades patientjournaler konsekutivt från tre strokeenheter. Insamlade data inkluderade patientens ålder och kön, nutritionsstatus, multisjuklighet, komplikationer efter inläggning av PEG och trycksår. Data analyserades och presenterades med beskrivande statistik som medelvärde (± SD) förutom vårdtidens längd och antal dagar från inläggning på sjukhus till PEG-inläggning som presenterades som median (range). För korrelationsanalyser beräknades Spearman-korrelationskoefficienter. Båda studierna utfördes i enlighet med Helsingforsdeklarationens riktlinjer.

Resultat: I studie I granskades 201 patientjournaler, medelåldern för patienterna var 79 ± 7 år. I studie II granskades 161 patientjournaler, medelåldern för patienterna var 82,2 ± 7 år. De viktigaste resultaten från denna avhandling är följande, i studie I var OD en indikation för PEG hos 86% av patienterna. Medianöverlevnaden i denna grupp var cirka 4 månader och 30-dagarsdödligheten var 22%. Patienterna

kategoriserades i sju olika diagnosgrupper. Patienter med stroke och andra neurologiska sjukdomar såväl som patienter med malignitet hade den kortaste överlevnadstiden. I studie II var OD en indikation för PEG hos 95% av patienterna. Nästan 80% av patienterna uppfyllde kriterierna för European Network criteria for multimorbidity. Morbiditet och multimorbiditet korrelerade med vårdtidens längd (p = <0,0005). Komplikationer efter inläggning av PEG förekom hos 69% av patienterna. Mer än en komplikation inträffade hos 33% patienterna. Antalet komplikationer var relaterat till 33% såsom viktminskning (p = <0,046) och Body Mass Index (BMI) förändring (p = <0,018). En viktig upptäckt var att trycksår identifierades hos 50% av patienterna, vilket dokumenterats i patientjournalerna. Dokumentation av patienternas nutritionsstatus saknades i journalerna. Mer än hälften av patienterna i studie II saknade en dokumenterad nutritionsbedömning vid både inskrivning och vid utskrivning.

Slutsatser: OD hos patienter med neurologisk sjukdom utgör en majoritet av patienterna som fick PEG i studie I. Överlevnad efter inläggning av PEG varierade för patienter inom de sju olika diagnosgrupperna som identifierades i studie I. Dessutom var svårighetsgraden av sjukdomarna okända och det var även okänt huruvida sjukdomarnas svårighetsgrader kan ha påverkat överlevnaden. I studie II saknades väsentlig information om patientens nutritionsstatus vilket kunde ha påverkat patientens nutritionsbehandling under sjukhusvistelsen. Trycksår identifierades hos 50% av patienterna vilket var en oväntad komplikation och indikerar att det finns ett behov av ytterligare forskning. Denna studie indikerar att implementering av nutritionsriktlinjer i vården av geriatriska patienter med PEG behövs.

LIST OF SCIENTIFIC PAPERS

I. Malmgren A, **Wärn Hede G,** Karlström B, Cederholm T, Lundquist P, Wirén M, Faxén-Irving G. Indications for percutaneous endoscopic gastrostomy and survival in old adults. *Food & Nutrition Research 2011; 55; 6037.*

II. **Wärn Hede G,** Faxén-Irving G, Ödlund Olin A, Ebbeskog B, Crisby M. Nutritional assessment and post-procedural complications in older stroke patients after insertion of percutaneous endoscopic gastrostomy – a retrospective study. *Food & Nutrition Research 2016; 60; 30456.*

CONTENTS

LIST OF ABBREVIATIONS

OD	Oropharyngeal Dysphagia
EN	Enteral Nutrition
PEG	Percutaneous Endoscopic Gastrostomy
BMI	Body Mass Index
TIA	Transient Ischemic Attack
CNS	Central Nervous System
PSD	Post Stroke Dysphagia
TMS	Transcranial Magnetic Stimulation
ESPEN	The European Society for Clinical Nutrition and Metabolism
MNA	Mini Nutritional Assessment
MUST	Malnutrition Universal Screening Tool
MEOF-II	Minimal Eating Observation Form-version II
NRS-2002	Nutritional Risk Screening Tool
GLIM	The Global Leadership Initiative on Malnutrition
LOS	Length of Stay
EPUAP	European Pressure Ulcer Advisory Panel
UTI	Urinary tract infection
DN	Department of neurology
DG	Department of geriatrics
DM	Department of internal medicine
PU	Pressure ulcer
ALS	Amyotrophic lateral sclerosis
MNA-SF	Mini Nutritional Assessment- Short Form
ICD	International Statistical Classification of Diseases and Related Health Problems

1 INTRODUCTION

In my profession as a nurse, I have met the most sick and frail patients. They suffer from underlying diseases which have consequences for a long period of time or for the rest of their lives. Prolonged disease increases the risk of malnutrition, sarcopenia and frailty. When working at a geriatric stroke rehabilitation ward my interest aroused in how the patients' nutritional status was assessed and how their nutritional requirements were met in the care team. A growing interest to develop routines for the treatment of patients who had eating difficulties became a central issue in the care unit. Risk assessment routines were developed to facilitate identification of patients who were at risk of malnutrition or were malnourished.

Assessment of the patient's health condition and how nursing care was affected due to patient's nutrition problems resulted in the development of nurse's documentation where the nursing process was self-evident. Nursing care plans were developed and introduced at the ward. The nursing care plans were standardized, including nursing diagnoses, nursing goals and nursing interventions related to nutritional problems e.g. risk of malnutrition and risk of aspiration Nursing care plans regarding other nursing areas were also developed. OD at a severe state causes problem to manage intake of food and liquid and is associated with a risk of aspiration. Alternative ways to give nutrition such as enteral nutrition were therefore discussed with patients and close relatives.

The research studies have given me the opportunity to deepen my knowledge about patients who suffer from OD and are treated with EN by PEG. Nutritional problems that occur when the patient suffers from a disease that causes OD and when enteral nutritional becomes a life-sustaining treatment is essential to gain knowledge about.

2 BACKGROUND

2.1 The aging population

In Sweden, the aging population is increasing. In 2017 two million residents were 65 years and older (1). The public health among older residents has improved and more residents assess their health as good. The average length of life has increased with 2.5 years for residents 80 years and older. Better living habits and living conditions are contributing factors (2). A healthier lifestyle in recent years have led to reduced cases of coronary heart disease and stroke among older people (3). However, the years of illness will not disappear, instead the years of illness are moving forward in time which result in more healthy years before support from health care services and social services arises (4).

2.2 Morbidity and multimorbidity in older people

Old age is a predictor of morbidity and multimorbidity, when reaching 80 years and older common health diseases i.e. cardiovascular diseases, psychiatric diseases, diabetes, osteoporosis and cancer increases. The proportion of older people with more than one medical diagnosis increases with old age as well as the risk of chronic illnesses increases with old age (2, 5, 6). The European General Practice Research Network definition for multimorbidity states that "Multimorbidity is defined as any combination of chronic disease with at least one other disease (acute or chronic) or biopsychosocial factor (associated or not) or somatic factor. Any biopsychosocial factor, any risk factor, the social network, the burden of disease, the health care consumption, and the patient's coping strategies may function as modifiers (of the effects of multimorbidity). Multimorbidity may modify the health outcomes and lead to an increased level of disability, decreased quality of life and frailty" (7, p 9). The prevalence of multimorbidity in older patients varies between 37%-75% with a significant association between multimorbidity and factors such as age, frailty and increased health care utilization (8, 9). The concept frailty is used to describe a person of high biological age, reduced physiological reserves and increased vulnerability in case of acute illness or when the person's social network collapse (10).

2.2.1 Stroke

Stroke, one of the most common diseases affects 15 million (11) people worldwide, whereof 5 million people die and 5 million become permanently disabled (12,13). Stroke survivors may experience loss of mobility due to paralysis, loss of speech due to aphasia, impaired nutritional status due to OD and may experience confusion. Stroke survivors often become dependent of help from family or other

caregivers. In Sweden, stroke affects around 25 000 – 30 000 persons annually, of which 80% are ≥ 65 years old (14). Stroke is caused by disruption of the blood supply to the brain by either blockage (ischemic stroke) (85%) or rupture of a blood vessel (15%). The most important risk factors for ischemic stroke are high blood pressure, atrial fibrillation, tobacco use, unhealthy diet, physical inactivity and diabetes. The most important risk factor for stroke caused by rupture of a blood vessel is high blood pressure. Besides ischemic or ruptured stroke, about 10 000 persons annually suffers from transient ischemic attack (TIA). The symptoms of a TIA will pass within minutes up to 24 hours and gives a prediction of a later major stroke. Patients with ischemic stroke should be admitted to a hospital as soon as possible, within 4 to 5 hours for intravenous thrombolysis treatment. Signs of an acute stroke may be aphasia, hemiparesis, hemisensory loss, hemineglect, visual field deficit, gaze deviation and eye movement abnormalities, dysarthria and gait instability and incoordination (14,15). Early rehabilitation after stroke is important. A multidisciplinary based rehabilitation team consisting of reg. nurse, physician, occupational therapist, physiotherapist, speech therapist, social worker, psychologist and dietician gives the patient prerequisite to recover as much as possible (14). Detection and treatment of especially swallowing difficulties is essential in order to reduce the risk of nutrition-related complications during and after hospital stay.

2.3 Normal swallowing and dysphagia

2.3.1 Normal swallowing

To understand the complexity of swallowing a short description of normal swallowing is presented. Swallowing is a physiological reflex that comprises a complex interplay between more than 40 muscles and structures in the mouth, pharynx and esophagus. The muscle movements are controlled by cranial and peripheral nerves and are coordinated in the brain stem. Besides the muscles and nerves there are structures within the, pharynx, esophagus and the oral cavity i.e. teeth and saliva that are involved in the process of swallowing (16, 17). The swallow procedure is divided in four phases: oral preparation phase; oral transport phase; pharyngeal phase and; esophageal phase. In the first phase, the oral preparation phase, the food is processed and prepared by chewing and softened with saliva until a bolus is formed. The second phase, the oral transport phase, the bolus is transported through the oral cavity to the pharynx by the tongue. The third phase, the pharyngeal phase, is the most complex phase of the swallowing and is coordinated larynx to direct the bolus away from the laryngeal inlet. In the fourth phase, the esophageal phase, the bolus has entered the esophagus and is squeezed through the esophagus into the stomach (16, 17).

2.3.2 Dysphagia

Dysphagia is the medical term for swallowing difficulties, of Greek dys- which means impaired function or a disorder and the verb fagein which means eating. Dysphagia can be associated with several different types of abnormalities in the normal swallowing function of the mouth, pharynx or the esophagus. The major types of dysphagia can be regarded as neurological related e.g. stroke, Parkinson disease, multiple sclerosis or mechanical/structural e.g. heads and neck trauma, laryngeal trauma, head and neck tumors and cancer or other etiologies e.g. pharyngitis, neck abscesses, AIDS, sarcoidosis. Neurological conditions affect the signals of information to and from the CNS, resulting in disturbed function of the muscular and structural system. Mechanical/structural abnormalities interfere with the anatomical or mechanical/physiological system. Dysphagia predominates above difficulties due to impaired ability to handle and move bolus from mouth to stomach due to divergent motility, feeling or coordination. The concept of dysphagia is usually included in, for example, drooling, chewing difficulties, food remnant in the mouth and throat and failure to swallow saliva, medicine, food and liquid (18, 19). Dysphagia is a major complication after stroke, affecting 37-78% of the patients (20). Post Stroke Dysphagia (PSD) is thought to be due to damage to the cortex and subcortical structures. However, cortical re-organization could lead to swallowing recovery. Studies using Transcranial Magnetic Stimulation (TMS) have shown that pharyngeal musculature is represented bilaterally, but asymmetrically, in the cerebral cortex (21). OD can be defined as an interruption of the bolus movement from the mouth to the throat which is characterized by difficulties in initiating swallowing and impaired transport of bolus from the oral cavity to esophagus (22,23). Rofes et al. performed a study of 395 geriatric stroke patients in which they state that old age, previous stroke, high score at National Institutes of Health Stroke Scale (NIHSS) and large stroke lesion volume were risk factors for OD (24). To identify the risk of OD it is important to assess the patient's ability to swallow as early as possible in newly admitted patients (14,25,26,27). National guidelines elucidate that it is highly prioritized, according to proven experience, to continuously evaluate the swallowing ability (14). Furthermore, old age in combination with stroke and OD may contribute to negative outcome in the patients' care (26). Dysphagia improves spontaneously in most stroke patients (28). However, 14-50% of the patients still have swallowing problems after one week (28,29). Furthermore, patients have being identified with OD later in the course of their illness. One reason may be lack of bedside assessment. Patients who did not undergo assessment at the time of the hospital admission were found to have OD at six months after stroke (22,25). Aspiration in dysphagic patients is often not associated with a cough response or outward signs of difficulty in swallowing. This absence of any outward sign or distress is known as silent aspiration and has been reported as occurring in 15-39% of subacute dysphagic stroke patients and

in 2-67% of acute stroke patients (30,31). When oral nutrition no longer is possible EN is preferable if no contradictions exist (26). The European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines (32) states that when a patient needs EN for a longer period and has a functional gastrointestinal system, nutrition by PEG is the preferable route and is associated with fewer treatment failures and complications (33, 26).

2.4 Percutaneous endoscopic gastrostomy

PEG was originally described for pediatric use (34, 35) and is today a common way of supplying artificial enteral nutrition in adults. Feeding by PEG has increased world-wide due to a relatively uncomplicated routine. The main objective of EN is to maintain the patient's nutritional requirements (36, 37). EN should be considered as medical treatment and should be decided by the physician together with the patient and next of kin (26). Medical indications for PEG placement are OD due to neurological indications i.e. cerebrovascular disease, motor neuron disease i.e. amyotrophic lateral sclerosis, Parkinson's disease, head and neck cancer, head injury and intensive care patients (26, 37-39).

In a study of 324 geriatric patients who received PEG it was stated that the PEG-procedure is a minimally invasive procedure although the patients' prognostic factors should be considered before inserting PEG (40). The PEG-procedure eliminates the need for general anesthesia and the procedure also requires less instrumentation (41). An incision is made through the abdominal wall and a catheter is placed into the stomach through the incision. The catheter is fixated (Figure 1) with an internal bumper or stop plate inside the gastric cavity and an outer adjustable external bumper or stop plate to be held in position (35,36). When feeding or distributing medication to the patient an infusion device or a syringe is connected to the adapter of the PEG. Due to the complexity of older people with stroke and OD, the risk of complications after insertion of PEG cannot be neglected.

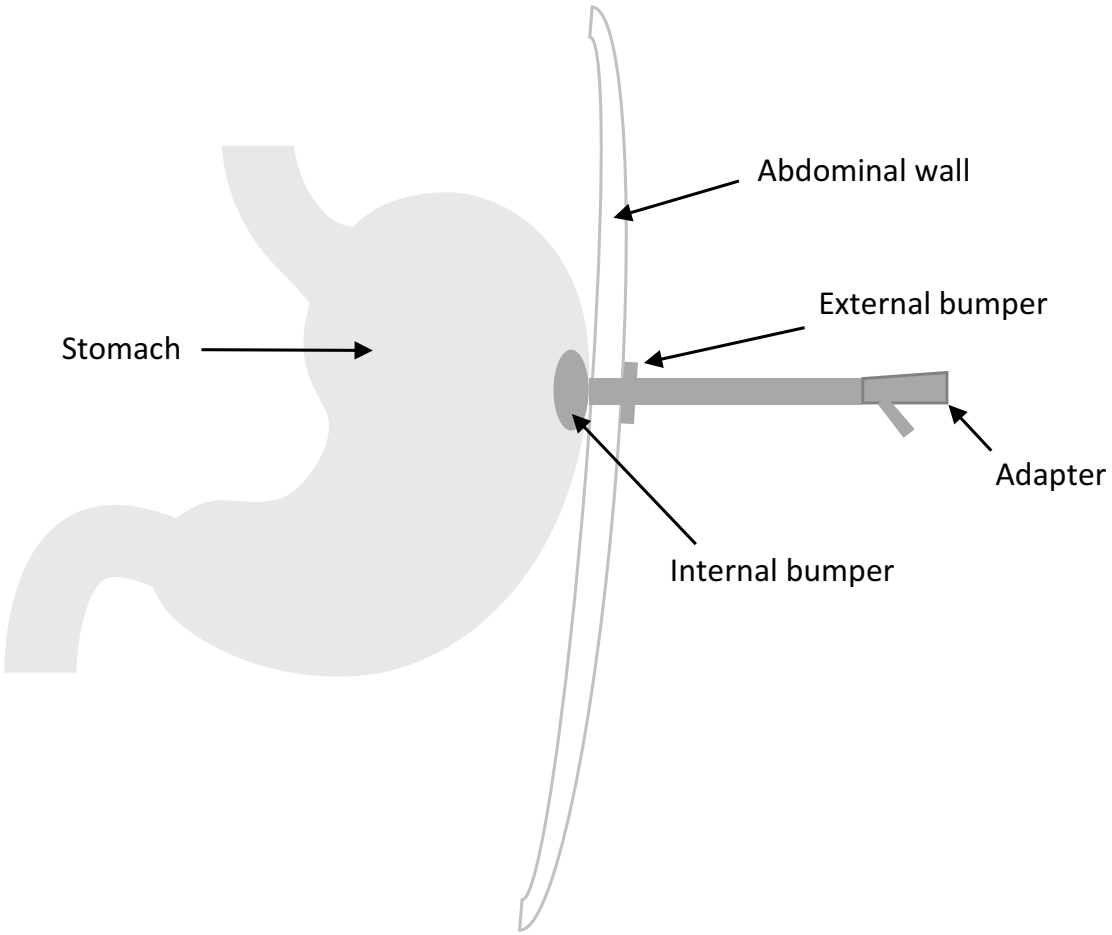

Figure 1. *Placement of PEG.*

2.4.1 Complications and survival after PEG

Complications after inserting PEG vary between different studies. Perioperative complications are rare (42-44). Common early complications are wound infection, fever, local pain, peristomal leakage, diarrhea, constipation, aspiration pneumonitis, peritonitis and. Early complications occurring within 48 hours up to 30 days after PEG insertion are reported in 2% - 38% patients in different studies (45-48). Late complications occurring from 72 hours up to one year after PEG insertion are reported in 20 – 28% of the patients in different studies (45-48). They are recorded as: local infections, PEG-tube displacement, blockage, leakage, constipation and diarrhea (45-48). Several studies report 30-day mortality of around 20% after placement of PEG (49-53). Kara et al. show that both early and late complications increased mortality risk after PEG insertion and that stroke was an independent risk factor for overall mortality after PEG insertion (54). Findings in a study of 174 older patients with stroke after PEG insertion showed a mortality rate at 66% in two years after stroke and PEG insertion (55). For stroke patients

PEG insertion was a significant predictor for 30- and 60 days hospital readmission and septicemia were the most frequent primary readmission diagnosis (56). The extent of complications after insertion of PEG together with swallowing difficulties causes healthcare professionals to carefully follow and assess the patient's nutritional status during the care period.

2.5 Nutritional assessment

Malnutrition among nursing home patients was highly prevalent and OD was identified as a major contributor to malnutrition (57). Similar findings have been described where OD affects the nutritional state of the elderly (58). Saito et al. describes dysphagia - malnutrition - neuromuscular dysfunction as a three-part hypothetically coherent condition where the three parts mutually affect each other, which can be difficult to break but not impossible (59). Therefore, it is pertinent to identify patients who are malnourished or at risk of malnutrition and to initiate appropriate person-centered nutritional treatment. The National Board of Health and Welfare (60) and ESPEN guidelines (25,61) recommend early nutritional screening/assessment including the following risk factors for malnutrition:

- unintentional weight loss (prior to admission)
- eating difficulties
- underweight (BMI kg/m2< 22 in patients > 70 years)

Nutrition assessment tools have been developed, for example Mini Nutritional Assessment (MNA), Malnutrition Universal Screening Tool (MUST), Minimal Eating Observation Form-version II (MEOF-II) and Nutritional Risk Screening Tool (NRS-2002). Common to most of these instruments are that they include parameters according to recommended early nutritional screening (62-67). European nutrition experts have presented "An ESPEN Consensus Statement" were it states that screening of the nutritional state is mandatory upon arrival at the health care unit, regardless of clinical specialty. Whether the patient has an acute or chronic condition upon arrival at hospital or nursing home, there is a risk that the patient develops nutritional impairment (68). To prevent frailty and malnutrition in geriatric wards and nursing homes, it is essential that nutritional screening, followed by assessment and if necessary early diagnosis of malnutrition is performed (69).

2.5.1 Nutrition care process

A healthy nutritional status is a prerequisite for preventing sickness and to regain health. The nutrition care process is a support for health care professionals to secure the nutrition care for the geriatric patient (60). The nutrition care process

(Figure 2) starts with a Risk assessment/nutrition screening and if the risk assessment/nutrition screening identifies the patient to be at risk of malnutrition the diagnostic procedure is initiated. In the diagnostic process an assessment of possible causes is considered. Possible causes may be OD, decreased oral hygiene, underlying disease, mode of feeding, decreased physical activity, gastrointestinal disorders, medical treatment and loss of appetite. An individual care plan for nutrition is created. Nutrition goals are recommended. The nutrition care plan should be developed by a multi/interdisciplinary team together with the patient. The nutrition care plan describes the nutrition therapy, monitoring the patient i.e. food intake, intake of energy and fluid, follow up on body weight and BMI, biochemical indices, physical function and quality of life. Finally, the nutrition care is evaluated, and the outcomes of given nutrition care must be communicated to the patient and in the team. On discharge the given nutrition care, including the whole care plan must be communicated to the next caregiver to secure continuation of the nutritional care and support (60, 70). Since 2015, the Swedish National Board of Health and Welfare states that every caregiver is obliged to have a nutrition care plan including assessment of the patients' nutritional status, prevention and treatment of malnutrition (71).

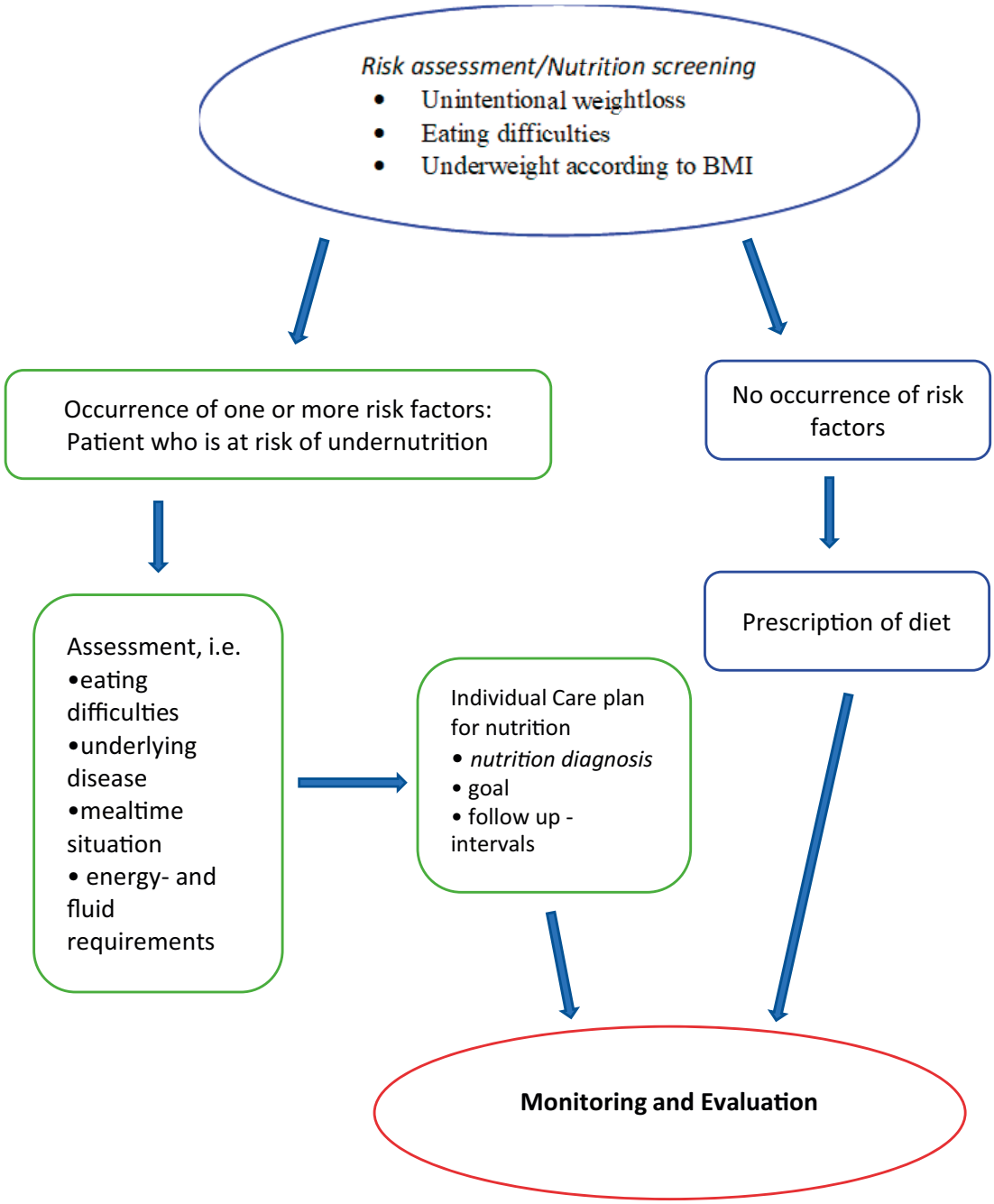

Figure 2. *The Nutrition care process.*

2.5.2 Malnutrition

Malnutrition is defined as a "condition when absence of or imbalance of energy, protein or other nutrients have caused measurable and adverse changes in the structure of the body, function of the body or progress of the disease" (60). Malnutrition is a worldwide concern (72) and there is growing evidence that the prevalence of malnutrition in geriatric patients is increasing (73). Pathologic changes of aging

such as chronic disease, depression, cognitive impairment, multiple morbidities, and polypharmacy play a significant role in the complex etiology of malnutrition in the elderly (73). Malnutrition causes reduced appetite and energy expenditure, fluid and electrolyte imbalance, altered levels of cytokines and hormones, delayed gastric emptying, and an impaired sense of smell and taste. Recently an expert group, The Global Leadership Initiative on Malnutrition (GLIM), published a consensus document of minimum diagnostic criteria for malnutrition. The five criteria that were identified by a majority of GLIM participants were, weight loss, low BMI, reduced muscle mass, reduced food intake or assimilation and disease burden/ inflammation (74). Malnutrition in geriatric patients are associated with negative outcomes such as increased risk of falling, mortality, length of hospital stays, low weight, using more medications, dependent on walking aid, had more depressive symptoms, poor functional status and increased mortality (75-77). Geriatric patients with underweight have a significantly higher mortality than patients with normal weight (78). Underweight is also associated with poor functional outcomes in stroke patients (79). Despite better living conditions and an increased average length of life, malnutrition or risk of malnutrition become a rising problem if the elderly person is hospitalized. Also, the prevalence of sarcopenia increases in patients with malnutrition and risk of malnutrition (80). Risk of malnutrition has been shown to be an independent predictor of mortality, length of stay (LOS) and higher hospitalization costs at 6 months post stroke (77). Malnutrition may lead to an increased LOS, in a review study the authors state that malnourished patients did not improve during hospital stay which indicates that nutritional interventions were insufficient (81). In a study of 138 patients admitted for post stroke rehabilitation 11 patients died during follow up. Deceased patients were significantly older and had a lower BMI, lower hemoglobin, lower serum albumin levels and lower rates at nutritional and functional assessment (82). Both OD and malnutrition are major concerns and predicts that the patients' nutritional state should be assessed on admission to hospital after stroke (83). In a meta-analysis, Cheng et al. identified possible risk factors, i.e. malnutrition on admission, dysphagia, previous stroke, tube feeding, and reduced level of consciousness related to malnutrition in stroke patients (84).

OD or not, stroke patients are at risk of malnutrition (85, 86) which in turn is a risk factor for further complications e.g. pressure ulcer (87, 88). Moreover, malnutrition has serious implications for recovery and is associated with increased morbidity and mortality, prolonged length of stay (LOS) and increased healthcare costs (89). European guidelines urge that all stroke patients should be screened for risk of malnutrition on admission (25). An individualized nutrition care plan is of importance (26) and future research in the field of nutritional care for stroke patients appears to be of high priority (90). Documentation of the care delivered is a ubiquitous and important aspect of medical, nursing care and other health professionals.

2.6 DOCUMENTATION IN PATIENT RECORDS

The patient record is a clinical communication tool to provide data, support the quality of care and to guarantee an adequate care for the patient (91). According to Swedish regulations, health care professional's documentation should describe the assessment and individual needs of the patient, planned and performed interventions, evaluation of given care and a discharge note (92, 93), which also complies with the nursing process (94). The nursing process is a well-known structure for nurses. The nursing process has been described in various contexts since the 1960s. Its application has been described as a structure for documentation in patient records, as a support for the nurse to organize nursing care and as a support in education (95). The nursing process consists of five phases that provides a systematic tool for nurses in planning the care for the patient and to document the care. To conduct the nursing process, a minimum of two persons is necessary – the nurse and the patient and/or family.

The phases are as follows:

- Assessment – the purpose of this phase is to identify and obtain information and involves the nurse's collection and clustering of subjective and objective information of the health status of the patient.
- Diagnosis - specifies the nursing diagnosis as a clinical judgement concerning the human response to health conditions and life processes. The nursing diagnose concludes the assessment component. It is the basis for planning, interventions and to evaluate the nursing care.
- Planning - of interventions and nursing outcome the goal is used to identify the intended nursing outcomes of the nursing care. When stated a nursing goal, the nurse plans the nursing interventions to meat or achieve the goal. This step is the nurse's and the patient's determination of the nursing care plan to assist the patient towards the goal of optimal wellness.
- Implementation - of nursing interventions the planned interventions should be implemented and performed as they are described by the nurse. This step is the completion of the interventions to accomplish the goal of optimal wellness.
- Evaluation - of nursing interventions related to the goal and nursing diagnosis evaluation is always considered in terms of how the patient responded to the planning of care in relation to goal achievement and realization of expected outcomes and implemented nursing interventions. (94).

Educational activities to promote documentation (96,97) and implementation of documentation curriculum improve accuracy in the documentation system. Poor documentation impacts on the patient's safety and the continuity of care which

could cause delays in giving proper treatment and cause a poor standard of care (98,99). Nutrition assessment and documentation of the patient's nutritional status is essential for the best possible outcome of the nutrition care.

2.6.1. Documentation of nutritional assessment

In a study by Volkert et al it was stated that both physicians and nurses failed to recognize malnutrition and nutrition-related problems in geriatric patients despite knowledge that risk of malnutrition is common in this patient-group (100). Insufficient documentation of the patients' nutritional status increases the risk of malnutrition and complications. Findings of insufficient documentation are reported regarding nutritional assessment. In two interview studies, it was found that older patients were not routinely nutritionally assessed (101) and that the documentation of nutritional treatment and the transfer of nutritional information between heath care settings was lacking (102). Health professionals have an obligation to document the patients' needs and treatment, yet both registered nurses and assistance nurses in hospital and nursing homes experiences that documentation of nutritional information was insufficient and arbitrary (102). Guerden et al. show in their retrospective analysis of 506 nursing records that the documentation was complete in 68 of the 506 records (103). An intervention program with education in older patient's nutritional needs and nutritional care improved nutritional status and functional capacity of older residents in community care (104). Knowledge of the value of nutritional assessment, nutritional treatment and follow-up in older geriatric patients receiving PEG regardless of health care setting needs to improve.

3 RATIONALE

Geriatric inward patients with PEG and stroke patients with PEG due to OD constitute the group that is the focus of this thesis. The average life expectancy of older persons increases, and they live additional years without disease. Nevertheless, they may experience from the fact that the health condition fails later in life. The vulnerability of older persons becomes apparent when disease or illness result in failure to manage daily lives. A failing state of health involves contact with healthcare professionals in various occupations. During hospital stay, it is the healthcare professionals' that in teams should meet the patient's needs. The reasons why nutritional problems occur during hospital stay may be several e.g. disease or altered life situation or medical treatment. Impaired nutritional status and delayed nutrition treatment during the hospital stay contribute to an increased risk of complications. Knowledge of the patient's nutritional problems is the basis for being able to analyze and to treat the patient. Prevention of malnutrition in patients with eating difficulties is essential. Unless the nutrition condition is followed and evaluated daily during the hospital stay, problems may occur that have negative consequences for the patient's recovery. A consensus among the professions involved in the patient's care, both in the hospital and the municipality together with the patient and / or the relatives about treatment with PEG is essential. A debatable reason is illustrated by Golan et al. where 83% of physicians (n = 72) stated that PEG was inserted in the patient in order to facilitate the discharge of the patient to a nursing home (105). In the same study, the interviewed physicians stated that insertion of PEG should not have been an indication for discharge to nursing homes (105). A PEG procedure should not be decided based on which healthcare provider should care for the patient. Communicating nutrition information between healthcare providers is most important for continuity of care. In case of failure to report assessment, information of diagnosis, planning and implementation of interventions, continuity of care may be lost. A comprehensive knowledge of PEG, its indications and the complications that may occur provide an opportunity to design the care and treatment based on knowledge of the patient's condition.

4 AIM

The overall aim of this thesis was to increase the knowledge of the process of older patients receiving PEG regarding indication, survival, documentation of nutrition assessment and complications.

4.1 Aim study I.

The aim of the study was to examine the indications for and survival in a consecutive group of elderly individuals who had received PEG.

4.1.1 Research questions, study I:

- What are the indications for PEG in older patients?
- What is the survival time after PEG insertion in older patients?

4.2 Aim study II.

The aim of the study was to describe to what extent nutritional assessments were performed and documented in the records of older patients with stroke treated with EN by PEG. A secondary aim was to identify documented post-procedural complications after PEG insertion during hospital stay.

4.2.1 Research questions, study II

- To what extent were nutritional status documented in older patients with oropharyngeal dysphagia treated with EN by PEG?
- What types of post-procedural complications were documented after PEG insertion?

5 METHOD

5.1 Design

Both study I and study II were carried out with a retrospective descriptive cross-sectional study design, by auditing patient records.

5.2 Setting and sample

Study I refer to patients who underwent PEG insertion between January 1997 and December 2000. A total of 201 records for geriatric patients were consecutively included. Data was collected from four different chart systems, both manual and electronic from the Endoscopy unit at Karolinska University Hospital. The electronic record system was linked to the Central Register of Population Registers, which included information about when the patient died. The patient records were collected and reviewed by the first author. In each journal, the patient's personal data was deleted, and the patient record was provided with a specific code before being reviewed.

Data were systematically collected from the patient records according to predetermined criterion:

- medical diagnosis
- indications for PEG
- operating time
- time for removal of PEG
- time of death

Study II refers to patients who underwent PEG insertion between January 2006 to December 2009. A total of 161 patient records for geriatric patients admitted to three stroke units were retrieved. All patients received PEG due to OD after stroke.

The included stroke units were:

- department of neurology at Karolinska university hospital, Huddinge and Solna.
- department of geriatrics at Karolinska university hospital, Huddinge.
- department of internal medicine at South hospital in Stockholm, Sweden.

When collecting patient records local secretaries at each department were assisting and the first author attended. Information from the electronic record systems was retrieved from the two clinics at the university hospital and from the department of internal medicine. In each journal, the patient's personal data was deleted, and the patient record was provided with a code before being reviewed. Figure 3 shows an overview over the studies.

Data were systematically collected from the patient records according to predetermined criterion:

- age, gender, length of stay, indication for PEG.
- body height, body weight, BMI (kg/m2), weight loss.
- primary and secondary medical diagnosis.
- post-procedural complications.

In study II, reviewing of all records was carried out twice. During the first review, the first author observed that PU was identified and documented in the records. After discussion in the research group, it was decided to conduct a second review of the patient records with the purpose of mapping the occurrence of pressure ulcers. Based on how the pressure ulcer was described in the patient record, a classification was made from categories I-IV according to the International European Pressure Ulcer Advisory Panel (EPUAP) Category I defines a nonblanchable erythema; Category II defines partial thickness skin loss; Category III defines full thickness skin loss and Category IV defines full thickness skin loss (106).

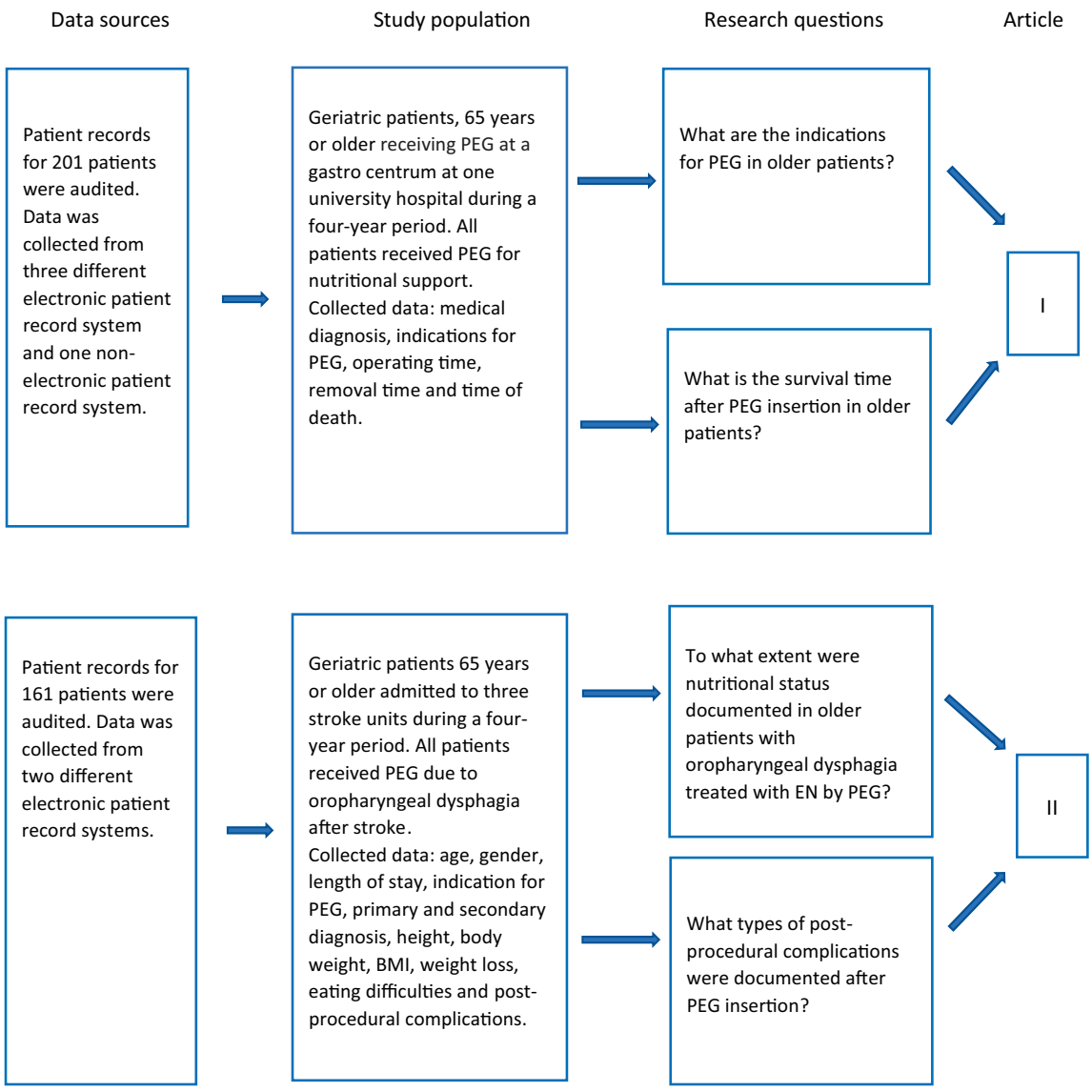

Figure 3. *An overview of the studies*

6 STATISTICS

6.1 Study I

Data were collected by the first author and downloaded into Microsoft Excel and means (SD), median (range) values were calculated for ages. For survival analysis, the Long-Rank test and Kaplan Meier curves was used. The SPSS and Statistica software programs were used. Results were presented as mean (±SD) and median with range. Survival curves show percent survival in relation to time. At the start, everyone is alive and when an individual die, the percentage of survivors decreases, and the curve goes one step down. Those who have not died at the end of the study are entered as censorship values.

In study I, the patients have been dichotomized in two age groups 65-79 years and 80 years and older. In statistical public reports in Sweden, population groups are often presented for the elderly as younger elderly (65-79 years) and the elderly elderly (80 years and older). All statistical differences with p values ≤ 0.05 were considered statistically significant.

6.2 Study II

The data were downloaded into Microsoft Excel, analyzed and computed in terms of frequencies and percentage. Statistical analyzes were made using the Statistica software package. The separation in age groups in study II has been adopted based on the same principles as in study I. For correlation analyses, Spearman correlation coefficients were calculated. Results were presented as mean (±SD). Number of days from admission to PEG insertion and LOS was presented as median (range). Significant level was set at $p \leq 0.05$.

7 ETICHAL CONSIDERATIONS

Both studies were descriptive and performed according to the Helsinki declaration guidelines (107).

At the time of data collection for study 1, which originally was a master thesis study, it was not compulsory to obtain approval from the Institutional Review Board. Data collection and handling of the information was consistent with ethical guidelines.

Study II was approved by the regional ethical committee at Karolinska Institutet, reference 2010/950-31/1.

In order to ensure that patients' integrity was protected, it was important that journal entries were unidentified and provided with a code for each record. List with patient's personal information were kept inaccessible to non-project members. The collected information is presented so that it did not expose identity of patients whose records have been reviewed. In neither of the studies, any personal contact was made with the patients, published data only refers to studied records. No personal data are reported, all data are compiled based on encoded material. The patient record is a valuable source of information and knowledge which can be studied in order to develop and improve the care of this vulnerable patient group based on collected data. Scientific benefit with both Study I and II outweighs the risk of the patients whose records were audited.

8 RESULTS

8.1 Study I

The patients were 65 years or older who had received PEG for nutritional support. The patients, 107 males and 94 women with a mean age of 79 years (range 65 - 95). Seven diagnosis groups emerged and formed the basis categorization of the patients (Table 1).

8.1.1 Indications for PEG

Indications for PEG were categorized into three groups:

1. Dysphagia, in 86% of the patients.
2. Inability to eat, in 6% of the patients. The reason for PEG insertion was extreme weakness, motor and mobility problem, and fatigue due to the illness.
3. Nutritional support, in 4% of the patients. Enteral nutrition was used in combination to oral intake.

Data concerning indication for PEG was missing for 4% of the patients.

8.1.2 Survival

For 10 of the 201 patients, the date for removal of PEG was not available. Following this exclusion, the survival analysis was performed for 191 patients. Median survival in the whole group was 123 days with a range of 0 - 1713 days. Patients with Mb Parkinson and dementia had the longest survival. Patients with other neurological diseases and malignant esophageal obstructions had the shortest survival. They showed a 1-year mortality of 77%. After six months 44% of the patients, in the whole group, were still alive and after twelve months 33% of the patients, in the whole group, were still alive.

Categorization in diagnosis groups, survival in the various diagnosis groups and 30-days and 90-days mortality are shown in Table 1.

Table 1. Categorization in diagnosis groups, 30- and 90-days mortality.

Diagnoses	Number of patients (%)	30-days mortality, %	90-days mortality, %"
Stroke	97 (49)	22	46
Malignant esophageal obstruction[a]	33 (16)	23	42
Miscellaneous	23 (12)	17	39
Dementia	16 (8)	25	37
Other neurology disorders[b]	13 (6)	23	54
Mb Parkinson	12 (6)	9	18
Other malignancies[c]	5 (2)		
No data available	2 (1)		
All patients	201	22[d]	42[d]

"[a]esophageous, lung, pharynx, larynx, mouth, thyroid and vocal cords.
[b]mainly Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS).
[c]occurred with or without dysphagia.
[d]in 10 of the 201 patients, date for removal of PEG was not retrievable, these were excluded from the survival analysis and mortality analysis."

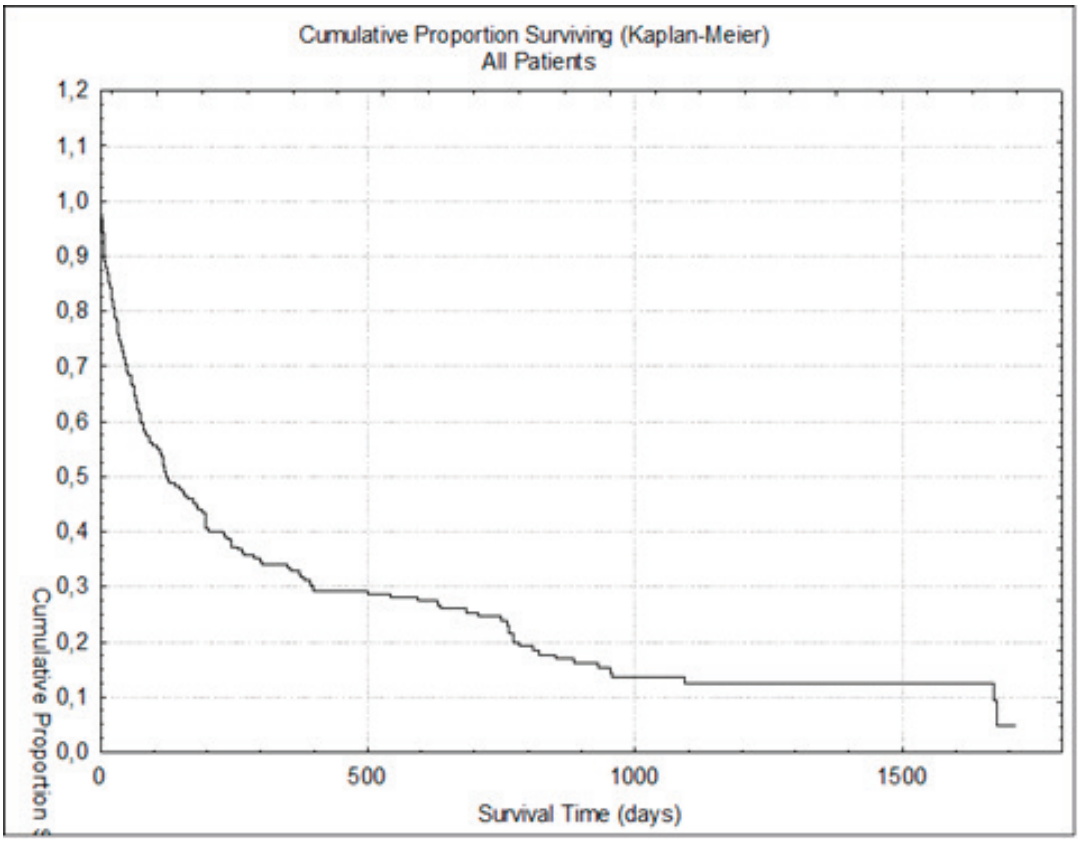

Figure 4. *Survival in days for all patients, n=191.*

Dichotomization of patients into < (n=99) and ≥ 80 (n=92) years of age showed no difference in one-year mortality in the whole group, patients over 80 years of age showed a 1-year mortality of 70% and patients 79 years and younger showed a 1-year mortality of 64% (nonsignificant). Patients with dementia ≥ 80 years showed a 1-year mortality of 73% and patients with dementia < 79 years showed a 1-year mortality of 33%, (p =0.025).

8.2 Study II

The patients were 65 years and older and with a mean age of 82.2 (±7.03) years. Ninety-two (57%) of the patients were women. One hundred and four (65%) of the patients were 80 years and older.

Mean number (range) of days from hospital admission to PEG insertion was 19 days (1-187) for all patients, in DG 25 days (13-88), in DN 22 days (1-187) and in DM 14 days (2-38).

The median LOS was more than one month in DG (40 days) and in DN (36 days) and around three weeks in DM (21 days). Six percent of the patients deceased during hospital stay. On admission 75% of the patients lived in their own accommodations. At discharge an identical number of patients were transferred to nursing homes.

8.2.1 Morbidity and multimorbidity

Ischemic stroke was reported in 88% of the patients and the remaining 12% of the patients suffered from hemorrhagic stroke. Seventy-five percent of the patients had concomitant cardiovascular diseases and 20% of the patients had type II diabetes mellitus.

Almost 80% of the patients fulfilled the European Network criteria for multimorbidity and 58% of the patients had four or more (range 4-10) medical diagnoses. Infections (i.e. pneumonia, septicemia, erysipelas, urinary tract infection (UTI)) during the hospital stay were reported in 51% of the patients. Thirty-six percent of the patients were diagnosed with pneumonia and of these 30% of the patients developed pneumonia during the hospital stay. Aspiration was identified to be the major cause of pneumonia.

Morbidity, the number of diseases for each patient, and multimorbidity correlated to the LOS (rho= 0.37, $p < 0.005$). Morbidity was negatively related to weight loss at discharge (rho= -0.30, p=0.019) and to BMI at discharge (rho= -0.40, p=0.004) (DG, DN).

8.2.2 Nutritional assessment

Body weight (kg) was assessed on admission in 50% of the patients at all three stroke units (92% at DG, 51% at DN, 34% at DM). At discharge, body weight was assessed in 38% of the patient's altogether, (88% at DG, 57% at DN, 1.5% at DM). During hospital stay a weight loss of approximately 2 kg was recorded in both DG and DN. In DM, only one of sixty-eight patient's body weight was assessed at discharge (Table 2). In statistical analysis age correlated negatively with weight on admission (rho= -0.26, p=0.020).

On admission, the mean BMI (m/kg2) was 23 in the whole group of patients. However, in DG the mean BMI (±SD) was lower i.e. 19.4 (±1.6) in patients >80 years old and 21.9 (±3.5) in patients 65-79 years old and decreased during the hospital stay. BMI was assessed both on admission and at discharge in 29% of the patients. None of the patients at DM had a documented BMI at discharge (Table 2).

Table 2. Body weight and BMI on admission and at discharge in stroke patients from three different wards.

	DG n=25	DN n=68	DM n=68	All n=161
Weight on admission				
65-79 yrs, mean ±SD, (n)	54.1 ±8.7 (5)	74.2 ±14.7 (14)	62.2 ±26.5 (8)	
≥ 80 yrs, mean ±SD, (n)	60.5 ±13.5 (18)	63.5 ±10.7 (21)	64.8 ±12.2 (15)	
All, mean ±SD, (n)				64.2 ±14.8 (81)
Weight at discharge				
65-79 yrs, mean ±SD, (n)	55.0 ±6.5 (4)	69.5 ±14.7 (18)	n=0	
≥ 80 yrs, mean ±SD, (n)	58.3 ±12.5 (18)	65.6 ±14.1 (21)	56.0 ±0 (1)	
All, mean ±SD, (n)				63.7 ±14.0 (62)
BMI on admission				
65-79 yrs, mean ±SD, (n)	19.4 ± 1.6 (4)	25.7 ± 4.7 (10)	24.6 ± 1.8 (6)	
≥ 80 yrs, mean ±SD, (n)	21.9 ± 3.5 (18)	23.8 ±3.9 (13)	22.8 ± 3.0 (14)	
All, mean ±SD, (n)				23.2 ± 3.8 (65)
BMI at discharge				
65-79 yrs, mean ±SD, (n)	18.6 ±2.0 (4)	25.3 ± 4.1 (10)	n=0	
≥ 80 yrs, mean ±SD, (n)	21.2 ±3.6 (18)	23.7 ± 4.2 (18)	n=0	
All, mean ±SD, (n)				22.7 ± 4.2 (50)
Weight change during stay				
65-79 yrs, mean ±SD, (n)	-2.4 ±3.8 (4)	-1.9 ± 3.0 (11)	n=0	
≥ 80 yrs, mean ±SD, (n)	-2.2 ±3.8 (18)	-1.9 ± 3.5 (14)	n=0	
All, mean ±SD, (n)				-2.0 ± 3.4 (47)
BMI change during stay				
65-79 yrs, mean ±SD, (n)	-0.8 ±1.2 (4)	-0.7 ± 1.1 (8)	n=0	
≥ 80 yrs, mean ±SD, (n)	-0.7 ±1.2 (18)	-0.6 ± 1.4 (12)	n=0	
All, mean ±SD, (n)				-0.7 ± 1.2 (42)

DG= Department of Geriatric Medicine, stroke rehab unit.

DN= Department of Neurology, stroke unit.

DM= Department of Internal Medicine, stroke unit.

8.2.3 Post procedural complications

After PEG insertion post procedural complications were reported in 69% of the patient records. More than one complication was reported in 33% of the patients. Complications occurred more frequently in patients > 80 years of age. Table 3 displays PEG-related complications and gastrointestinal complications. PEG-related complications were identified as complications due to PEG insertion and gastrointestinal complications were identified as complications due to the EN treatment.

Table 3. Post procedural complications, local pain and pressure ulcers after PEG insertion in patients, age groups 65-79 and 80+, from three different wards. Data collected from patient records.

	DG n=25	DN n=68	DM n=68	All n=161
PEG-related*1				
65-79 yrs, n=(%)	4 (16)	10 (15)	5 (7)	19 (12)
≥80 yrs, n=(%)	7 (28)	11 (16)	11 (16)	29 (18)
Gastrontestinal-related*2				
65-79 yrs, n=(%)	1 (4)	9 (13)	3 (4)	13 (8)
≥80 yrs, n=(%)	5 (20)	5 (7)	2 (3)	12 (7)
Pain, local				
65-79 yrs, n=(%)	2 (8)	10 (15)	4 (6)	16 (10)
≥80 yrs, n=(%)	5 (20)	7 (10)	6 (9)	18 (11)
Pressurre ulcer				
65-79 yrs, n=(%)	5 (20)	17 (25)	6 (9)	28 (17)
≥80 yrs, n=(%)	14 (56)	18 (26)	21 (31)	53 (33)

DG= Department of Geriatric Medicine, stroke rehab unit. DN= Department of Neurology, stroke unit. DM= Department of Internal Medicine, stroke unit.

*1 PEG-related complications i.e. leakage, bleeding from stoma, local inflammation, PEG self-extubated, ileus, PEG in abdomen, wound complication, reflux in PEG, PEG-tube blockage and local abscess.

*2 Gastrointestinal complications i.e. diarrhea, constipation and nausea/vomiting.

8.2.4 Pressure ulcers

PU were documented in 50% of the patients and was more frequent in male patients. A total of 116 PUs was identified. Thirty patients had more than one PU and one patient had PU within all categories I-IV. The most common PU categories I-II were more frequent in patients' ≥80 years (Table 3). For a total of 75 patients PU in category I was identified. Of these, 49 patients were ≥80 year's old. For 35 patients PU in category II was identified whereof 19 were ≥80 years. The number of complications was related to weight loss (rho= -0.33, p=0.046) and BMI change (rho= - 0.42, p=0.018).

9 DISCUSSION

Collecting information about the patient by obtaining data from patient records is a common method. In this thesis, data is collected through reviewing patient records. The main findings of this thesis are: In study I OD was an indication for PEG in a majority (86%) of geriatric in-ward patients and median survival in this group was about 4 months. Patients aged ≥80 had the shortest survival. In study II OD was an indication for PEG in a majority (95%) of stroke patients. Postprocedural complications occurred in more than half (69%) of the patients, several patients contracting more than one complication. Assessment and record keeping of the patients' nutritional status was poorly performed in two of the three stroke units. For more than half of the patients in study II a nutritional assessment was lacking both at admission and at discharge.

9.1 Indications

The results in study I and II support findings from other studies regarding OD as indication for PEG. In Sweden study II is a landmark study that presents data regarding the number of days from hospital admission until insertion of PEG. Persons with Amyotrophic lateral sclerosis (ALS), Parkinson's disease, Stroke and cancer in head and neck-region or oropharyngeal cancer are diseases causing OD being treated with PEG (108, 109, 110) A study by Wirth et al. of 197 geriatric patients who received PEG showed that OD and stroke was the main indication of insertion of PEG (111). In the same study With et al. found that the mean number of days from admission until insertion of PEG was 17,5 days. This result is in accordance with study II were the mean number of days from hospital admission to PEG insertion was 19 days. Anderloni et al. report from their study of 950 geriatric patients receiving PEG that it was mostly indicated by dysphagia due to stroke. They also report that the mean time of days between the request of PEG and the procedure was 6,5 days which they thought was too long (112). There is no information in study II when the assessment regarding OD was performed after hospital admission and weather any delay in assessment was the cause of delay in request for inserting PEG.

9.2 Survival

As shown in study I, 22% of the patients died within 30 days. Similar results have been reported in studies for stroke patients who received PEG (54, 55). A retrospective study of 401 patient records at a Medical Center (mean age 68 years) showed that 30-day mortality was 5% after PEG insertion. Patients with neurologic disease group including dementia, Parkinson's disease, neuromuscular disease,

and hypoxic brain damage showed significantly lower early mortality rate than stroke and malignancy (113). Most of these diagnose groups in the study by Pih et al. are similar to the diagnose groups identified in study I in this thesis. However, regardless of the diagnoses, study I does not show the severity of the diseases and whether that could have affected the mortality of the patients. Barbosa et. al. report that mortality after PEG insertion in geriatric patients is high, of 135 patients with neurological diseases, malignancies, brain injuries and Parkinson's disease 14% of the patients died within 30 days after the procedure (114). Neurological disorders, especially in older people, can adversely affect the outcome of an acute illness. In view of the mortality rate in patients with OD, it is important to assess swallowing ability on a regular basis as well as nutrition assessment, and to address identified health problems. Studies need to clarify if continuous follow-up of nutritional and swallowing assessment as a decision support for prescribed nutritional therapy in older patients receiving PEG is beneficial to survival of the patients.

9.3 Multimorbidity

In both Study I and Study II, the patients who underwent PEG-insertion suffered from neurological disease to a high degree, oropharyngeal dysphagia and multimorbidity. As described in study II 80% of the patients fulfilled the criteria for multimorbidity and 58% of the patients had four or more medical diagnoses. Multimorbidity in older people with stroke contributes to a complexity that makes the older person more fragile and prone to complications which can affect morbidity and mortality. In study II 120 of 161 patients were living in their own accommodation on admission and the same number of patients were discharged to nursing home. Of the 161 patients 58% met criteria for multimorbidity. It is not studied how many of the 120 patients who were discharged to nursing homes also met the criteria for multi-illness which would have been valuable information. Multimorbidity in combination with stroke will challenge the health care community resources in coming years, both in acute settings and in long-term facilities (115). A recent review study report that stroke is a risk factor in complex states of multimorbidity, preferably in combination with e.g. Alzheimer's disease, depressive disorders and depression (116). One well-known fact is that the risk of stroke increases in diabetics, although the magnitude of risk varies depending on the study population (116) which referrers to the result in study II were 20% of the patients had type II diabetes mellitus. In study II morbidity and multimorbidity correlated to LOS in hospital. All these conditions reflect the complexity of these patients which is of great importance for planning a person-centered nursing and medical care during hospital stay.

9.4 Oropharyngeal dysphagia and PEG

OD due to neurological disease was a dominant factor for the insertion of PEG and stroke was the most common diagnosis in the studies in this thesis. PEG is a known and accepted method for maintaining the nutritional status when the patient needs nutritional support for an extended period (61). Neurological diseases, where stroke is one of the most common diagnosis, is a frequent cause of OD in older people (58). A retrospective study demonstrated that neurological disease was the main indication for the insertion of PEG in 92% of cases, where 48% of the patients had dysphagia due to stroke (117). In study I, three indications for insertion of PEG were identified. OD was the predominant cause followed by the inability to eat independently due to weakness, impaired mobility and fatigue due to disease. Similar results have been demonstrated in a study by Pih et al. showing that stroke and malignancy, mainly in the oral and pharyngeal regions, are the most common indication for insertion of PEG (113). Carrión et al. stress that older persons should be systematically screened for OD as their study showed that OD was an independent risk factor for malnutrition among older persons admitted in acute settings (118). For most patients in study I and study II the cause of OD was stroke, findings that are in good agreement with international studies.

9.5 Complications

Complications occurred in more than half of the patients in study II and in one third of the patients more than one complication occurred. Pih et al. state that age ≥ 70 and diabetes mellitus were risk factors for complications (113). Complications in study II are classified as PEG-related complications and gastrointestinal complications. The most common PEG-related complications were local pain and local bleeding. Gastrointestinal complications reported was diarrhea, nausea/vomiting, leakage. Ermis et al. show similar results regarding PEG-related complications in their study of 81 geriatric patients (117). In Study II, it was found that 80% of patients met the criteria for multimorbidity and that more than half of the patients had more than four medical diagnoses. Seventy-five% of patients had concomitant cardiovascular disease and 20% of patients had type II diabetes. Infectious diseases during the treatment period were identified in half of the patients. Maintaining an adequate nutritional status in this fragile patient group is essential to reduce the risk of complications, not only after PEG insertion but also in the future. An unexpected, but important finding in study II was that in 50% of the patients PUs was identified. For all patients where PU were identified, there was no initial risk assessment performed or initial description of the skin's condition performed. Patients with impaired mobility are at a higher risk for PU development (119, 120). In study II, the number of days from admission to PEG insertion may to some extent explain both weight loss and the high prevalence of PUs. There are clear

and evidence-based guidelines for the prevention and treatment of PU for older people in order to reduce the risk of pressure damage (106). An important issue is that the patient and the patient's caregivers should be well informed regarding the PEG procedure. This information is essential when discussing insertion of peg with the patient and the patient's caregivers.

9.6 Nutritional assessment

All patients whose medical records were included in study II had an acute illness and eating difficulties. In most of the patients OD was stated as an indication for PEG. At two of the three stroke units in study II, information of the patients' nutritional status was lacking. Body weight was assessed on admission in 50% of the patients and at discharge in 38% of the patients. BMI was assessed both on admission and at discharge in 29% of the patients. The purpose of assessing the nutritional state is to identify patients' needs for nutritional support. Agarwal et al. concludes that malnutrition increases with age and care level (121). Similarly, OD is a risk factor for malnutrition in older people with acute illness (118). Ostrowska et al. reports that 78% of patients age ≥65 had a reduced nutritional status diagnosed with Mini Nutritional Assessment - short form (MNA-SF) (122). At the same time, Gomes et al. concludes, with a statistical significance the relationship between malnutrition risk and 6-month mortality, the higher risk of malnutrition, the higher mortality rate (77). Only nutritional assessment is not enough, but a nutrition care plan and follow-up are needed in patients in risk of malnutrition. Furthermore, a Danish study notes that screening for eating difficulties is also essential in older patients in hospitals and in municipal care. (69). A process-oriented approach and care should facilitate the care of the patient during hospital stay. As reported earlier in this thesis the documentation of the patient's nutritional status was missing to an excessive extent. Registered nurses, dieticians and physicians together plan and organize the nutrition treatment for the patient (123). Each profession in the health care system has a legal duty to document the care of the patient (92). In a Danish focus group study six categories emerged of health professionals' experiences on nutrition and documentation. Among the six categories identified was lack of clear nutritional care responsibilities that affect how daily care was performed. Another category was lack of clinical leadership and priorities that makes nutritional care invisible. Yet, another category was that different attitudes towards nutritional care leads to differences in the quality of nutritional care (124). Nutritional assessment is one of the most important assessments the registered nurses perform when the patient arrives in health care facilities. Secondly, an important task is to monitor the patient's nutritional status during hospital stay. And thirdly, to plan and execute the nursing care for the patient. If this is not done the patient will not get the nutrition care the patient is entitled to which may cause complications and longer hospital stay. A recent Swedish study shows that the patients are assessed

regarding their nutritional status but there is still missing analysis of underlying causes (125). All the patients in study II underwent a PEG procedure to ensure the patients nutritional status and paradoxically, documentation of nutritional assessment was lacking. Continued research on the follow-up of the nutritional status both before and after PEG insertion is required. Guidelines for monitoring patients' nutritional status are available. Further research of how nutrition guidelines are implemented in health care is essential.

9.7 Methodological considerations

The primary purpose of the patient record is to be a source of information between and within professions in order to safely care for the patient, which means that the patient record is primarily a working tool. The patient record is also an important document in legal contexts and not least a source for obtaining information for research and education purposes.

Journal review as a data collection method requires that the reviewer is familiar with reading patient records. One strength regarding examination of patient records in both studies was that both reviewers (first author) had a long-standing experience of reviewing patient records. In this thesis, journal review has been the source of data collection for analysis. Another strength with the studies was that records for all patients who received PEG was included. Collection of records was based on ICD codes for stroke and insertion of PEG, which is why the chance that records are not included may be considered small.

Data collection of study I was carried by the first author, electronic journal and supplementary information in paper journal were reviewed. When data collection for study II was carried out, the legal protection for how patient data was handled in research context in Sweden was tightened, so access to parts of the patient record was limited. The first author did not have access to the electronic medical record system for collecting the patient records, instead the first author was assisted by administrative staff at each clinic.

Both studies were conducted as cross-sectional studies based on patient records for people receiving PEG, collected during a four-year period. In neither of the studies there was a control group to compare collected data with. A control group of patients with stroke and OD who do not receive PEG cannot be considered ethically justifiable. In contrast, a control group constituting another diagnostic group that received PEG could have been a control group for e.g. occurrence of complications and whether changes in the nutritional status had occurred during the hospital stay. When reviewing patient records, regardless of which data is collected, it is always second-hand information that constitutes the data to be

collected and analyzed by the researcher. A patient record is designed based on a standard for which information should constitute the basis of information to describe the patient's condition. Biases in collected data from patient records are described as selective deposit which means that a complete set of documents are not stored and selective survival which means that stored documents and records are not complete (126) which was the fact in study II.

In order to be able to compile and analyze collected data, it is required that the requested data is recorded. In study II it emerged that significant data regarding the patient's nutrition status was not always recorded during the patient's care period. Information of the severity of illness and cause of death is not collected in study II. Such information had provided an overall picture of the patient group since many of the patients in Study II met the criteria for multimorbidity.

An additional limitation was that no checking of another reviewer to strengthen the internal validity of the studies was not done. An audit tool was not produced for the collection of data from the records. An audit tool tested by several reviewers and compared between the reviewers to achieve consistency in the information collected had increased both the reliability and validity in both studies. On the other hand, the inclusion criteria of the studies were well-discussed, motivated and recorded before data collection started. Instead of posting collected information in a separate review instrument for each journal, an Excel file was used for registering collected data for each record separately.

9.8 Conclusions and further research

OD in patients with neurological disease constituted most of the patients who received PEG in study I. Survival after PEG insertion varied for patients in the seven different diagnose groups. It is important that we consider the results of our studies in selection of the patient who will receive PEG. Furthermore, in study I the severity of the patient's diseases are unknown and whether the severity of the disease could have had an impact of the mortality of the patients. Information of survival duration and post procedural complications is important information to involve both the patient and the caregiver in the decision of inserting PEG. In study II essential information of the patient's nutritional status was missing which could have had an impact the patient's nutritional treatment during the hospital stay. Study II contribute to the knowledge that there is an imminent risk that nutritional compromised patients may be unidentified and not correctly cared for. Although the study's results are based on data from several years ago, indications for insertion of PEG and assessment of the patient's nutritional status as quality indicators

is essential to provide good care for the older patient. The identified frequency of pressure ulcers which was an unexpected complication indicates that there is a need for further research regarding older patients with stroke receiving PEG and prevalence of pressure ulcer. There is a need for further research to understand health care providers knowledge and attitudes to assess and perform follow-up of the patient's nutritional status and documentation. This study also indicates that implementation of nutritional guidelines in the health care of geriatric patients with PEG is needed.

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